

A Message from the ICC Chair, Valerie Strohl

Dear Governor Daniels,

n behalf of the members of the Interagency Coordinating Council on Infants and Toddlers, I am pleased to submit the annual report of the ICC.

During the 2004-2005 grant year, the First Steps system provided services to over 19,000 children and their families, at an average cost of \$2,950 per child, well within national averages for early intervention services. First Steps growth remained relatively even for the second year in a row.

Administrative changes occurred mid-way through the contract year, and a stakeholder group made up of ICC members, previous ICC Chairs, parents, providers, and other key personnel worked together to make system change recommendations.

First Steps stakeholders continue to work diligently to hold costs, increase efficiency and contain growth, but keeping in mind our commitment to providing services to our most vulnerable population and their families.

This report includes a "fact sheet" section which reviews the First Steps mission and vision. The remainder of the report is organized around the five themes

by which our activities are measured: child find, supervision, family-centered services, natural environments, and transition.

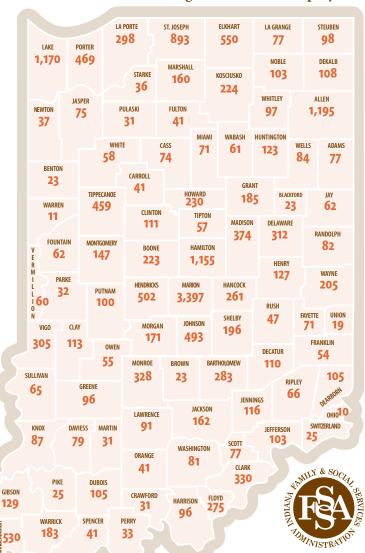
As First Steps continues to evolve, the ICC will be there to provide

to provide expertise and counsel to our state partners.

July 1, 2004 to June 30, 2005

Statewide Child Count

An aggregate total of 19,432* children received services through Indiana's First Steps system.



Data from July 1, 2004 to June 30, 2005

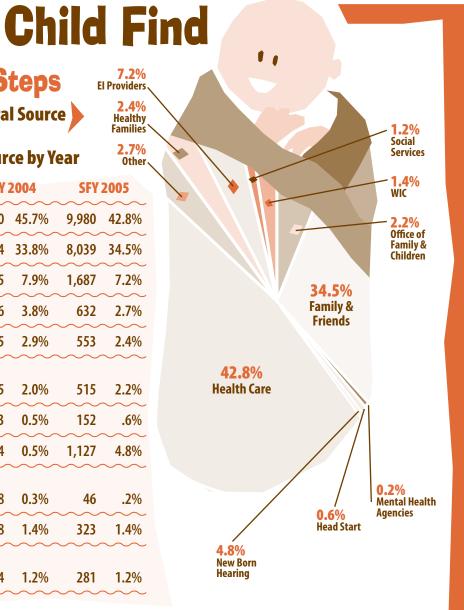
*County numbers reflect children who lived in more than
one county in report period.

Indiana First Steps

SFY 2005 Primary Referral Source

Primary Referral Source by Year

	SFY 2003		SFY	SFY 2004		SFY 2005	
Health Care	9,588	48.2%	9,640	45.7%	9,980	42.8%	
Family & Friends	6,455	32.4%	7,124	33.8%	8,039	34.5%	
El Providers	1,226	6.2%	1,675	7.9%	1,687	7.2%	
Other	747	3.8%	806	3.8%	632	2.7%	
Healthy Families	575	2.9%	615	2.9%	553	2.4%	
Office of Family & Children	491	2.5%	425	2.0%	515	2.2%	
Head Start	100	0.5%	103	0.5%	152	.6%	
New Born Hearing	Screen-	0.0%	114	0.5%	1,127	4.8%	
Mental Health Agencies	33	0.2%	58	0.3%	46	.2%	
WIC	453	2.3%	298	1.4%	323	1.4%	
Social Service Agencies	238	1.2%	244	1.2%	281	1.2%	



Eligibility*

7.2% El Providers

2.4% Healthy Families

2.7% Other

Description	SFY	2003	SFY	2004	SFY 2	2005
15% Delay in 2 or more Developmental Domains	2,917	22.0%	3,747	28%	4,416	32.4%
20% Delay in 1 Developmental Domain	7,091	54.0%	6,995	53%	7,109	52.1%
At Risk	688	5.0%	597	4%	471	3.5%
Medical Conditions	2.390	18.0%	2,167	16%	1,640	12.0%
Total	~·~	~~~~	13,506	~~~	13,636	
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Indiana First Steps Average Age at Referral

	SFY 2003	SFY 2004	SFY 2005				
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Average Age of Referral	13.8	13.9	14.3				
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Supervision

ECCS Summary of Activities for FY 2004

During FY 2005, the Early Childhood Comprehensive System (ECCS) planning project finalized a Strategic Plan for Indiana. The Core Partners developed 3 major goals for the ECCS Strategic plan using information from previous Needs Assessments, community forums and subcommittees. They are 1) Young children birth through five and their families are a policy, program and resource priority, 2) Every family with young children birth through five has access to quality, comprehensive resources and supports, 3) Resources and supports for young children birth through five are coordinated, cost effective, culturally and linguistically competent, and community based. Objectives being undertaken to meet the goals include a) All children will be covered by a source of payment, whether public or private, for medical and developmental services that are identified by the medical home, b) Parents have the necessary information, support and knowledge about child development and are able to recognize their child's progress, c) All children in Indiana will have a medical home, d) Families have timely access to resources and supports to address their child's health, safety and developmental needs, e) The medical home will facilitate developmental, behavioral and mental health screening with appropriate treatment and referrals to community resources, f) A central clearing house will be established that includes information about resources and supports at the state and local level for families of young children and providers of early childhood services, and g) Quality resources and supports are integrated to create a coordinated, accessible early childhood

All Sources of Funding for Early Intervention Services: Identification and Coordination of Resources

Sources of Funding Amount of Fund Federal		Services and/or Activities ng Supported by Each Source				
Federal Part C	\$8,557,112	Infrastructure & System Support, Limited Services				
Medicaid Federal	\$9,942,650	El Medical Services, Intake, Eligibility, Claims, Personnel Development & Training, Quality Assurance, Child Find, System Coordination				
TANF Federal	\$12,746,438	El Non-Medical Services				
State						
Early Intervention	\$6,120,392	All services and Activities				
Medicaid State	\$4,544,371	El Medical Services, Intake, Eligibility, Claims, Personnel Develop- ment & Training, Quality Assurance, Child Find, System Coordination				
State Supplement	\$12,358,669	All Services				
TANF State	\$11,488,673	El Medical Services				
MCH/CSHCS State	\$240,525	Intake and Eligibility				
Local						
Private Insurance		See Cost Participation & Insurance section on next page				
Other(s), Non-l	Federal					
Family Cost Participation Co-payments \$782,091		Services (Not IFSP, Evaluation, Service Coordination, Assistive Technology)				
Total Early Intervention Support	\$66,780,920	Contact: by phone at 317-232-1144, 800-441-7837 (toll-fre or web at www.state.in.us/fssa/first_step				
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# Supervision cont'd

### **Complaint Data**

	Reporting Period	Total Number of Complaints	Number of Substantiated Complaints	Primary Provider Types	Federal Codes &/or Indiana Codes	Content of the Complaint	Finding	Resolution
	July 1, '04 t June 30, '0		_	Service Coordinator (SC)	34CFR303.23 470IAC3.1-10-2	Service Coordinator Responsibilities Service Coordinator Responsibilities	Substantiated for All	Disenrolled
				~~~	~~~	~~~~~~	~~~	~~~~
				Service Coordinator (SC)	43CFR303.344 470IAC3.1-11-4	Content of IFSP (transition) Content of IFSP (transition)	Substantiated for All	Disenrolled
			-5%	~~~	~~~~	~~~~~~	~~~~	~~~~
3				Service Coordinator (SC)	470IAC3.1-10-02	Service Coordinator Responsibilities Content of the IFSP (transition) Service Coordinator Responsibilities SC Responsibilities (transition)	Substantiated for all	Disenrolled
				~~~	~~~~	~~~~~	~~~~	~~~~
				Service Coordinator (SC)	34CFR303.23 470IAC3.1-10-2 43CFR303.344 470IAC3.1-11-4	Service Coordinator Responsibilities Service Coordinator Responsibilities Content of IFSP (transition) Content of IFSP (transition)	Substantiated for all	Periodic Review of SC Files—Performed by SPOE Personnel and State Staff

### **Cost Participation & Private Insurance**

In March of 2005, the Indiana General Assembly passed legislation to revise the cost participation schedule for family incomes over 250% of poverty. As in the past, families eligible for Cost Participation are not charged for Evaluation, Assessment, IFSP development and Service Coordination services. Families eligible for Cost Participation are charged for on-going therapeutic services, and families may request to have their income reviewed and updated.

First Steps has made progress in establishing billing to private insurance. In February 2005, First Steps billed Anthem for services through November 2004. As further plans are implemented, First Steps will continue to pursue access and billing through other private insurance plans.

### **Quality Review—Focused Monitoring System**

One of the lead agency's key responsibilities is providing general supervision of programs and activities served with early intervention funding. To enhance its ability to identify areas of need and to improve compliance with federal and state rules, Indiana has partnered with the National Center for Special Education Accountability Monitoring (NCSEAM) to develop a focused monitoring approach to general supervision. Focused Monitoring is a process that purposefully selects priority areas to examine for compliance/results. These areas are monitored by the lead agency through data analysis, on-site early intervention record audits, provider record audits, parent, provider and LPCC interviews and complaint investigations. The local LPCC and SPOE use this information to formulate quality improvement plans and quarterly updates of their progress. Technical assistance is provided to the local LPCC and SPOE by the Bureau Consultant.

## **Early Intervention Stakeholders Offer Expertise**

A group of twenty-five early intervention stakeholders was convened in early 2005 to assist the new administration with proposed system changes. The group covered a wide range of roles within First Steps including providers, parents, ICC members, state agencies, legislative appointees, and staff. The group met five times before June 30 to start the process with much discussion occurring in task forces organized around various topic areas. Work groups met regarding insurance billing, centralized reimbursement, Medicaid/MCO's, provider networks, service coordination, eligibility determination, assistive technology, and Home for First Steps. Final recommendations will be made during the next contract year.

# Supervision cont'd

### **System Outcomes Project**

#### Evaluation of Indiana's First Steps Early Intervention System

This report summarizes data collected during the period from July 1, 2004 to June 30, 2005. Data collected from families as they entered the system (N=6419) and exited the system (N=4114) is summarized below by outcome.

#### First Steps Early Intervention System Outcomes

#### Outcome 1: Children attain essential and important developmental skills.

A primary outcome of First Steps is that children make developmental progress in the cognitive, communicative, physical, self-help, and social/emotional areas.

- Seventy-eight percent of the children for whom both Entry and Exit information was available demonstrated an increase in the number of important developmental skills
- Ninety-three percent of children exiting from First Steps function independently in one or more of the 10 daily routines such as dressing or eating with an average of 5.26 routines demonstrated at exit as compared to 3.67 at entry.

## Outcome 2: Children participate in inclusive community activities, settings and routines.

As part of the Exit Interview, families were asked to identify to which community settings and activities their children had accompanied them in the past two weeks. A total of 13 different settings and activities were surveyed, including going to the grocery store, going to church or other religious service, child care, and visiting friends or neighbors. When surveyed, exiting families reported that:



- Most of the families (98.9%) had participated in two or more different community activities and/or settings in the past two weeks with their children; and
- On the average, these children routinely participated with their families in 5 or more of the 13 community activities, settings, and routines measured.

#### Outcome 3: Children (and families) are safe, healthy, and well-nourished.

Over 99% of exiting families reported the presence of all positive indicators for children's health such as seeing their doctor regularly and being up to date on immunizations. The same high percentage reported knowing about and following recommended household safety measures such as the use of smoke detectors, car seats and safe storage of poisons and firearms, as well as having knowledge of proper nutrition.

## Outcome 4: Families participate as members of the early intervention team and carry out recommendations that help them to help their child.

Close to 100% of exiting families know and understand the First Steps process, including the purpose of First Steps evaluation, assessment, and the IFSP; and felt they could participate as active members of their First Steps team.

## Outcome 5: Families are connected to other families and natural community supports for emotional support during self-identified times of need.

Exiting families were asked if they knew about how to access other families and/or community resources when needed for emotional support. Results from the survey of exiting families indicated that most of the time, the majority of families (99%) knew they could access at least one resource, and 23.7% knew of four or five (out of a total of five) resources they could access.

In addition, most exiting families reported that they had information and resources to meet needs in the areas of transportation (96.9%), housing (98.2%), jobs (96.3%), and education (97.7%). (Continued on next page)

# Supervision cont'd

#### Outcome 6: Families advocate by exercising their rights in requesting and choosing goals, services and supports.

Entering and exiting families were asked if they know and understand their rights under First Steps. Results from exiting families indicated that most (98.1%) do. Families in Indiana's First Steps system are presented with their rights at the beginning of each team meeting, felt comfortable in their knowledge from the beginning of their affiliation with the program, and exited feeling equally confident in understanding their rights. Entering and exiting families were also asked if they knew how to exercise these rights, including how to problem solve situations when disagreements arose with their service providers. Results from the survey of exiting families indicated that:

• 100% of the families reported knowing how to exercise their rights (e.g., share concerns and priorities, make program choices, request changes, and refuse permission);

 99.2% of the families reported knowing how to work together with their service providers to find a solution if they disagreed with them; and

• 18.5% of the families reported disagreeing with their service providers in the past three months, with 95.3% of those families reporting that they were able to work together to find a solution.

In general, most families exiting First Steps reported having the knowledge and skills to advocate for their child in requesting and choosing services and supports.



# **Transition**

ndiana's Transition Initiative for Young Children and Their Families works on improving transition experiences for children from birth through 8 years of age. Leadership is provided from the State Transition Team representing parents and state level agencies and programs involved in transition. Transition success relies upon collaborative relationships between agencies through interagency policies, procedures, and resources covering administrative support, staff development, and family and child preparation. First Steps providers and public schools are required members of local transition teams that also include Head Start and other agencies that transition young children. During this reporting period the transition staff worked on a number of projects to improve transition. The transition initiative provided support to local community transition teams through training, team development, planning, transition agreement development, and dissemination of useful transition materials and products:

- Written transition products were provided to all 92 counties, First Steps Clusters, Special Education Districts, and Head Start Programs.
- Ten community transition teams representing 25 counties continue to partner to improve community wide transition systems for young children and families.

- There was a 66% increase in the number of written agreements statewide. Ninety-three agreements were received, evaluated for the inclusion of 10 recommended components of an agreement and posted to the transition web site. These agreements represent 58 Head Start entities, 88 First Steps county entities, and 85 local education agency planning districts or school corporations.
- Eighteen written procedures and 35 products to support the transition process were developed in 7 First Steps Clusters covering 37 counties.
- Team training/meeting facilitation was provided to 10 transition teams covering 25 counties for 36 events.
   Approximately 440 attendees representing parents, Head Start, First Steps, Schools, child care and other early childhood providers participated.
- The transition web site: www.indianatransition.org, was launched in May, 2005. It provides easy access to transition information and resources. Over 5,523 requests were accessed from the previous site and the new site for this period.

The transition initiative links transition teams and others to transition materials and products at:

http://www.indianatransition.org.

# **Natural Environments**

Family-Centered Services

#### **Indiana's First Steps**

has long embraced the federal mandate of providing services in a child's everyday routines, activities, and places. Indiana's average days from referral to IFSP continue to decrease from 37.9 to 35.6.

Numbers of children receiving authorized services								
Service Type # of	children	Service Type	# of children	Service Type	# of children			
Assistive Technology	1,427	Nursing	63	Service Coordination	n 18,065			
Audiology	3,509	Nutrition	778	Social Work	198			
<b>Developmental Therapy</b>	9,725	Occupational Therap	y 6,958	Speech Therapy	10,811			
Health Services	0	Other Related Service	es 139	Transportation	12			
Interpreter Services	170	Physical Therapy	7,146	Vision	58			
Medical	3	Psychology	358	~~~~~				

## Family to Family Initiative

Family to Family (F2F) continued to grow and expand in 2004-2005. Through outreach and networking activities, F2F Regional Facilitators and parent Points of Contact accomplished the following: (contract period runs from October 1, 2004 to September 30, 2005).

- 1,179 direct contacts were made with First Steps families. 71 parent Points of Contact (POCs) were active during this contract period.
- 12 parent trainings were conducted in 10 different counties and topics included Point of Contact, Communications, Co-training and Transition
- A series of new informational booklets and brochures were developed this year, and nearly 6,000 pieces were distributed, including 3,453 support

brochures, 1,066 volunteer brochures, 437 training catalogs, 624 parent packets, and 330 booklets about starting a parent support group.

> • 12 issues of the First Words newsletter were published online for

> > • A new Family to Family website was developed to connect families to our

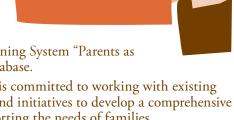
staff and volunteers, as well as additional resources of interest.

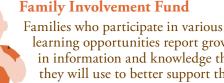
• 298 members were registered on the F2F list serv. 4,448 messages were posted to the list serv.

• 13 new families interested in Local Planning and Coordinating Council (LPCC) membership were identified.

• 11 new families were added to the Unified Training System "Parents as Co-trainers" database.

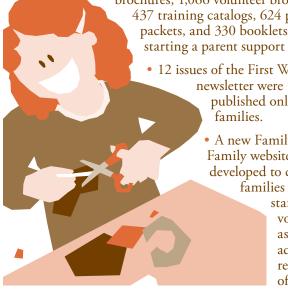
Family to Family is committed to working with existing systems, groups, and initiatives to develop a comprehensive approach to supporting the needs of families.





learning opportunities report growth in information and knowledge that they will use to better support their children with special needs. Seven hundred and ten (710) families accessed the family involvement fund to support their educational activities during this grant year.

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# Family-Centered Services cont'd



#### We're IN Step With Families

The ICC was the recipient of a Parent Leadership grant in 2004 and a team of ICC parents developed a plan to build on the existing foundation of family involvement in our First Steps system. A series of family celebrations were planned in several communities around the state designed to:

- Provide networking opportunities for First Steps families
- Gather feedback from families for the ICC
- Connect families to local resources
- Identify more parent leaders
- Connect with under-served populations

Events were held in South Bend, Evansville and Muncie. Children were welcome and they enjoyed playtime as childcare was available in an adjoining room. After having lunch with other families, parents were asked to join one of the small discussion groups led by parent leadership team members and answer a few questions about their First Steps experience. The goal of the gatherings was to get information from families about how to improve the First Steps system and take their experiences back to the state ICC. Lively conversations, great networking, and connections to local resources were the highlights of these gatherings.

### A Message from the Part C Coordinator—Dawn Downer

n reflecting upon this past year, First Steps continues to experience both change and ongoing development in many areas. While these dynamics can sometimes be challenging, both positive outcomes and stronger programmatic supports are anticipated for our early intervention system.

We have strengthened our quality assurance role through continuation of our focused monitoring efforts statewide. In addition, we are reviewing and maintaining service delivery methods that maximize quality service and meet the needs of Indiana's families and children. We are pleased with the parental involvement and support to address the changes that have been proposed and implemented in an effort to further build upon our early intervention system.

We look forward to continued partnerships with providers, parents and community members as we collaboratively define and deliver our goals and objectives in the coming year.

